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Encounters of help: disabled people negotiating help and participation in public spaces

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ABSTRACT

In the context of increased disability activism and changes in policy towards better accessibility for disabled people, the need for help from strangers remains misunderstood. Attitudes towards helping disabled people are shaped by the medical, charity and social models of disability that position disabled people as dependent, vulnerable, or self-sufficient resulting in difficulties managing situations when help may or may not be needed. To explore disabled people's experiences of encounters of help in public spaces, six interviews were analysed through the lens of the bio-psycho-social model. The findings demonstrated that disabled people negotiated their needs against allowances of the physical and social environments. They navigated a complex field of interactions related to expressions of demand and offer of help resulting in consented or unconsented help, or no help at all. Recommendations for helping behaviour and policy implications are raised in terms of supporting individually relevant participation of disabled people.

ARTICLE HISTORY

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KEYWORDS

Helping; disabled people; public spaces; participation; bio-psycho-social model; unconsented help

Points of interest

- How non-disabled people see and interact with disabled people depends on ways of thinking about disability (models of disability).
- The bio-psycho-social model explains disability as an interaction between the limitations of the body and barriers in the environment.
- This research found that when disabled people need help in public spaces, they carefully think about who to ask, how to ask and if to ask for help. They may or may not get the help.
- Disabled people get offers of help that they do not need, get the wrong help or do not get any help at all. It violates their rights, independence and freedom.
- Disabled people sometimes avoid situations and places where they might need help, or they rely on family members. To be independent, they use technology and aids. It helps when public places are adjusted and when others advocate for disabled people's needs and rights.

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Introduction

Although negative attitudes towards disability have improved, they persist as significant barriers for disabled people in living the lives they choose (Dixon, Smith, and Touchet 2018). Such attitudes can be driven by underlying models of disability, based on disabled people's perceived needs, unconsciously perpetuated through culture and the construction of policy that purports to empower and support disabled people (Retief and Letšosa 2018). According to the Stereotype Content Model (Cuddy, Fiske and Glick 2008), disabled people consistently rate low in perceived competence, (the perceived capability to pursue intentions towards others including characteristics such as competence, intelligence and skill) as historically they have occupied inferior societal positions. They rate higher in perceived morality and accommodating characteristics (the perceived intentions of disabled people towards others, those that benefit others, more than the self), eliciting paternalistic prejudice and the desire to protect, or help disabled people. Such stereotypes manifest thinking that can be exposed and explained through models of disability, and perhaps challenged and changed by more nuanced understanding of disability. The dominant medical deficit model views disability as an individual problem that leads to public and professional perceptions of disabled people as needing help due to their bodily limitations (Goodley 2017). Although the medical model has been beneficial in allocating interventions, it objectifies disabled people through a diagnostic/deficit lens. Likewise, the medical model's moralistic extension, the charity model, portrays disabled people as helpless, suffering victims of their impairment. Ultimately, in need of the public's help and generosity (Duyan and Centre of Excellence Defence Against Terrorism 2007), it leads the public to be paternalistic towards visibly physically disabled people, who often receive more help from strangers than desired (Olkin et al. 2019). This creates a discourse of presumed normality for non-visibly disabled people who may have their bodies policed about adjustments and help that they need (Kattari, Olzman, and Hanna 2018), such as accessing disabled parking spaces, often seen to be an abuse of the law, resulting in invisible barriers to their participation (Dorfman 2019). As Ysasi, Becton, and Chen (2018) discussed, how the stigmatizing effects of disability are not straightforward, and barriers might exist for people in disclosing non-visible disabilities or understanding the mobility needs of the visibly disabled. Some disabilities, such as dwarfism which is visible due to short stature, are often not perceived as a disability, but just a difference in size, resulting in their access to disabled facilities being challenged or denied (Pritchard 2020). Pritchard (ibid.) therefore argues that broader representations of disability are needed.

Conversely, the social model of disability has challenged these traditional perspectives, distinguished bodily impairment from disabling environments

(Beaudry 2016) and recognised and removed barriers in physical and social spaces (Oliver 2013). Nevertheless, it ignores how the lived and embodied experience of disability is shaped by bodily limitations (Beaudry 2016).

While the social model brings attention to overcoming barriers in the environment, it also emphasises independence as a value over the fact that disabled people might need help despite environmental adjustments. Help as such can be seen as something to avoid rather than to acknowledge as part of societal interdependence highlighted by the interactionist model of disability. While the recognition of rights, independence and prominence of disabled people in public spaces have increased (Nario-Redmond 2010; Wang et al. 2019), the visibility and independence may also present a conundrum for strangers as to whether to “help” disabled people or “let them stand on their own two feet” (Braithwaite and Eckstein 2003, 4). The assistive devices that provide greater independence in public spaces such as white canes and electric wheelchairs also act as visible markers that reinforce stereotypes of inability and weakness (Olkin et al. 2019). Pritchard 2020 also argued that such signifiers used on International Symbols of Access (ISA) reinforce what is considered a disability, creating a hierarchy of impairment. This hierarchy of the perceived need for help is highlighted by the disability hashtag #JustAskDontGrab (Enable Magazine 2019) whereby the experiences of unconsented help by strangers in public spaces is brought to the fore. Ignoring disabled people’s boundaries and voices and has psychological costs (Wang et al. 2019).

With the aim to overcome the reductionist view of disabled people’s experience as explained through a deficit lens by the medical model or environmental/attitudinal barriers as explained by the social models of disability, this research study aligns with the interactional perspective of the bio-psycho-social model that views a person’s level of functioning as an interaction between bodily functions and potential limitations, their environment (including attitudes and the inclination of others to help), and personal factors such as available resources and coping strategies (Mitra and Shakespeare 2019). Chan, Tsoi, and Chen (2025) similarly highlight the biopsychosocial perspective in their analysis of travel choices dependant on physical mobility needs as much as psychological aspects forming self-identity and anticipated guilt related to social perceptions and fear of social judgement. The biopsychosocial model enables the exploration of the wider contexts and tensions that influence the experiences of help, including the lived and embodied experiences shaped by impairment that might be overlooked when taking a singular medical or social model perspective (Shakespeare 2013). However, variants of the model have attracted criticism for being associated with the neoliberal ideals of ‘personal responsibility’ and ‘effort’ in health and recovery, ignoring the socio-structural contributions to disability with the motive to rationalise healthcare cuts and welfare reform (Hunt 2024). The bio-psycho-social model

allows a more holistic, humanistic and contextual exploration of experiences of help, where all layers are taken into account, rather than reduced to bodily function (individual problem) or social (problems in the environment). Personal factors such as coping strategies and individual resources add additional perspectives to disentangle the complex realities that perpetuate disabled people's experiences of help (Ghaemi 2009). The model is not used here to justify eligibility for help. It is applied as a way of recognising barriers in participation as situated in the body as well as in the dynamic interactions between the environmental systems and the individual.

Research on helping has conceptualised receiving help and support as a temporary need in stressful situations, however, disabled people may require differing instrumental support daily throughout life (Braithwaite and Eckstein 2003). Studies, mainly from the US but not exclusively, tend to focus on general helping experiences of non-disabled people and the costs of asking for help (DePaulo and Fisher 1980), and status relations in intergroup helping (Nadler and Halabi 2006), whilst few focus on microaggressions and the assumptions around disabled people needing help (Olkin et al. 2019), benevolent ableism (Nario-Redmond, Kemerling, and Silverman 2019), the consequences of confronting unwanted help (Wang et al. 2019), and the stigma of help-seeking in inclusive schools (Milinga and Possi 2018). Braithwaite and Eckstein's study (2003) explored how disabled people communicatively managed and balanced the need for instrumental social support against receiving unwanted help. This research study aimed to offer the participants an opportunity to tell their whole stories, share their views and preferences without assuming the direction towards positive or negative experiences with situations of help. As Biggeri and Ciani (2019) suggested, participating in research can reduce marginalisation and improve awareness about disabled people's lived experience. It hopes to revive interest in understanding the situations of negotiating help in public spaces from the perspective of disabled people and provide recommendations and insight into relevant policy implications for improvement.

Harmful stereotypes, misconceptions and bias in the way disabled people are viewed and interacted with by the non-disabled public (Seale 2013) may impact disabled people's experiences of help in public spaces. Moreover, implicit bias is found to be increasing (Harder, Keller, and Chopik 2019), and significantly relates to explicit understandings of disability as impairment, lacking independent status, and being compared to the norm (Friedman and Owen 2017), rather than being perceived as different but equal. However, focusing on individuals' implicit bias shifts the focus away from the political contexts in which inequalities are produced and maintained (Pritlove et al. 2019).

Poor accessibility remains a significant factor in disablement (Kapsalis, Jaeger, and Hale 2022), as many elements of design in public spaces do not meet accessibility standards (Open Access Government 2018). Additionally,

disability is not homogenous, and not all adjustments can accommodate all impairments (Shakespeare 2021). Hamraie (2013) noted that accessible design is a value-laden concept that produces material discursive effects for those excluded. For example, tactile pavement cues for white cane users indicating a nearby safe pedestrian crossing are not accessible for pedestrians using mobility aids. Similarly, Pritchard (2020) argued that despite accessible spaces being compatible with a variety of needs, access is often challenged to those who do not match stereotypical representations of disability, which subjects a 'hidden labour' in gaining access for those lower in the hierarchy of impairment. For the purposes of this study, we are using the term non-visible disability as defined by the UK government Disability Unit (2020) and used also by Hassard et al. (2024) in their research about disclosing non-visible disability. Regardless of accessibility exclusion/inclusion, human help and kindness remain key to accessibility for many in public spaces, as impairment still exists when barriers are removed (Crow 1992). Despite the many obvious benefits for disabled people of receiving help in getting needs met (Braithwaite and Eckstein 2003), they may experience negative feelings for receiving it (Milinga and Possi 2018). Furthermore, although public sector settings are covered by public sector equality duty in the UK (Government Equalities Office 2011) and may seem a safe option for help, they lack in disability awareness, awareness of their duties, and empathy towards disabled people, leading many to rely on informal and unpaid carers in public spaces, or face restricted lives without them (ONS (Office for National Statistics) 2022).

Braithwaite and Eckstein (2003) suggested that disabled people preferred to initiate a request for help or accept offered help, when it was clearly needed. However, this may depend on situational and personality variables (Milinga and Possi 2018). For some, the visibility of help in public spaces may be threatening to their pride and confidence (Nadler 2020); if they feel their physical safety jeopardised e.g. if helping directions are not followed, if it is patronising such as infantilisation, and if the helper is making a "big deal" out of it and drawing attention to the situation (Braithwaite and Eckstein 2003, 11–16).

Patronising, unwanted, and assumptive help is considered demeaning (Wang et al. 2019), causes embarrassment and perceived dependence (DePaulo and Fisher 1980), creates anxiety and discomfort (Hebl and Kleck 2000), affects physical health and wellbeing (Branco, Ramos, and Hewstone 2019), and results in social stigma and feelings of failure (Milinga and Possi 2018). Furthermore, disabled people are expected to be grateful and praise helpers (Braithwaite and Eckstein 2003; Olkin et al. 2019), even if help is not needed, and are accused of being rude, ungrateful, or over-sensitive when they decline help (Wang et al. 2015), which may discourage non-disabled people from offering help in future (Nario-Redmond, Kemerling, and Silverman 2019).

Although helpers may have good intentions, they may be oblivious to the reality of disabled people's experiences and unaware of their own prejudiced attitudes (Dixon, Smith, and Touchet 2018). Furthermore, helping others leads to increasing feelings of self-worth and self-esteem (Klein 2017), and positions helpers as high-status, independent, kind, and capable, and the helped as low-status and dependent (Van Leeuwen and Täuber 2009), which may be problematic to disabled people's self-identity, especially if help is required daily. Moreover, negative experiences may become so ingrained, disabled people may "just put up with them" (Moss and Frounks 2022, 10). This is problematic because it violates disabled people's human rights (UN DESA 2006), diminishes progress in the drive to make societies inclusive and may suggest why popular hashtags such as #JustAskDontGrab (Blind Abilities 2018; Enable Magazine 2019; Kavanagh 2018) receive high traffic, offering solidarity, and a safe place to vent negative feelings about such experiences, providing opportunities to educate non-disabled people in how to offer help.

The study offers a bio-psycho-social systems perspective on encounters of help, acknowledging barriers in the physical and social environments as well as limitations related to visible and non-visible disability. Understanding interactions between the individual and the environment aims to shed light on situations of help.

Methodology

Qualitative research methods were selected to produce an in-depth insight into helping experiences by engaging those affected (Clark et al. 2021). Semi-structured interviews were conducted as the research aimed to analyse and untangle complex, sensitive, and diverse human interactions (Roberts-Holmes 2018), to enhance trust and openness (Ashton 2014) and to empower participants by acknowledging, validating, and amplifying their voices (Hutchinson 2001).

Six in-depth interviews lasting an hour each were conducted online, for comfort, safety, and the greater accessibility in using adapted equipment at home (Osborne 2019).

A purposive sampling approach was taken to recruit participants over the age of 18, who considered themselves disabled, through social media, which has been proven an effective means of economically identifying and recruiting from hard-to-reach populations (Darmawan et al. 2020; Whitaker, Stevelink, and Fear 2017). Following the initial low response rate, disability organisations were invited to share the advertisement which increased participant response, emphasising the importance of a trusted mediator in research recruitment processes especially in the current climate of aggravated vulnerability of disabled people online (Alhaboby et al. 2017).

The research aimed to be inclusive as championed by Oliver (1996), by moving away from the ‘medical gaze’ that has labelled and derogated disabled people, by rebalancing the power relations, researching ‘with’ not ‘on’ them, avoiding reproduction of power differentials. The shared experience of disability between researcher (first author) and participants facilitated a richer dialogic exchange (Chaudhry 2019). Participants shaped the research during the process of interviewing by sharing experiences that were unique and significant to them (Raspa et al. 2020). Participants indicated that they found the process empowering and wanted to be involved as it mattered to them. They were asked to self-define their disability and request any adjustment necessary for them to participate.

Seven participants expressed interest in the research and six took part, consisting of three visibly impaired males with ages ranging from 20 to 70 years and three female non-visibly disabled participants between 30 and 50 years. Participant 1 was female, of white British origin, mainly non-visibly, physically and neurologically disabled. Participant 2 was female, of black African origin, non-visibly physically and cognitively disabled. Participant 3 was male, of white British origin, visibly physically paralysed. Participant 4 was male, of white British origin visibly physically disabled (wheelchair user). Participant 5 was male, of white British origin visibly physically disabled, severely (sight impaired). Participant 6 was female, of white British origin non-visibly physically disabled.

This allowed the researchers to gain an insight into a variety of different experiences and situations without an attempt to generalise due to the implications of small sample size (Staller 2021). The interview schedule provided a framework for the initial analysis of participants’ experiences. However, participants were encouraged to share experiences that were important to them adhering to the interpretative approach (Noble and Mitchell 2016), thus further themes were created inductively.

Ethical considerations

Ethical approval for the study was granted by The University of Suffolk on the 17 November 2022. Participants were interviewed by the first author, who was aware of the sensitive nature of the topic and its ability to bring to light difficult emotions, dependant on the nature of participants experiences (NDA 2009). An empathetic and compassionate approach, and the identification of the researcher’s shared experience of disability engendered more trust and greater openness (Clark et al. 2021), “building similitude and generating critical dialogue that is beneficial to social justice”, that can help bridge methodological gaps (Chaudhry 2019, 754). Although the interviewing researcher shared commonalities with participants in being disabled, disability is not a homogenous group, with each person inhabiting other social identities

besides disability, which may create different experiences. A social identity map was used (Jacobson and Mustafa 2019), to critically reflect upon and acknowledge the researcher's own positionality, assumptions and experiences, and closeness to the topic to alleviate these and become more open to participants' unique experiences (Schweber 2016), and thus promote a richer interview, analysis, and interpretation. Although the researcher's visual impairment may have been unmarked as a disability initially, due to intersectional differences and privilege e.g. being a white, female, middle aged, higher education student, self-disclosure alongside unplanned technical barriers facilitated deeper dialogic exchange in the co-creation of knowledge, without privileging the knowledge and experiences of either party (Chaudhry 2019).

Results and discussion

Research findings are presented thematically and discussed in relation to theory and other published studies with the aim to contextualise the narratives within the disability discourse. The participants had similar needs for help despite differences in the visibility of disabilities. Narratives of all participants were analysed together, but when visibility led to different experiences this was noted. Encounters of help are analysed as an interaction between the strategies undertaken by the disabled person and the public's behaviour in situations requiring help.

Strategies used in managing independence and help

Asking staff or people who are alone

Participants used various strategies when deciding whom to ask for help. Such strategies play a significant role in soliciting and managing help from strangers in public spaces as found also by Braithwaite (1987), (quoted in Braithwaite and Eckstein 2003, 3). For example, indicators of friendliness:

I would kind of try and make eye contact if somebody makes eye contact with me and they look friendly then. I'll smile and if they smile back then I will ask for help.
(Participant 1, mainly non-visibly disabled)

Perceived safety was also important:

I decide who to ask by picking a person that looks like a nan/grandma over fifty-ish as I personally feel they are safer hopefully. (Participant 6, non-visibly disabled)

or connecting attributes e.g. ethnicity.

I think I look for some attribute which kind of connect you with that person.
(Participant 2, non-visibly disabled)

People who seemed that they would not be disturbed were approached:

I generally ask employees if I'm in a setting where staff may work such as a cafe because it's part of their role to help the customer. I sometimes ask people who are by themselves because then I'm minimising any disruption because there's not more than 1 person involved, and I also like it to be a private thing. (Participant 4, visibly disabled)

Participants' assessment of helping situations can be understood through the lens of social exchange theory (Roloff 2015). Giving and receiving help can be both rewarding (in getting help, and helpers' raised self-esteem) and costly (in terms of cognitive effort, emotional cost, their perceived status, and helpers' time and effort).

Using technology, mobility aids and disability adjustments in public spaces

The use of technology helped achieve greater independence, functioning and confidence and may also reduce the need for help in public spaces by minimising or removing barriers in the environment e.g. orientation apps that give greater confidence in finding a sense of location in space.

I find technology is a good addition to helping me to say, you know, I'm coming up to a Road or Avenue and it gives me an orientation of where I'm at. Even then, sometimes. It's not wholly accurate but detailed enough. (Participant 5, visibly disabled)

As well as ordering apps that get trays to tables without having to explain/justify why help is needed.

Ordering on your phone is brilliant at restaurants and bars... because; One, it gets rid of interactions that are not needed, and Two, it gets that drink to my table without me having to carry it. (Participant 1, mainly non-visibly disabled)

Similarly, Steel (2022) noted that, assistive technology may reduce limitations in body functions, however, human help is still needed. Technology is not without problems due to technical faults and discontinuations that requires new apps to be installed and learned. This is problematic when the benefit of using technology is discretion and therefore decreases awareness of the need for help.

One app I'm using, it's called soundscape. I don't know if you've come across that one, but unfortunately that one's going to be withdrawn in June. (Participant 5, visibly disabled)

Four physically disabled participants used a variety of mobility aids, either permanently or intermittently, these included walking sticks, white canes, guide dogs and wheelchairs. Although aids offered greater independence with accessing public spaces and sometimes lessened the help needed, they also increased offers as they draw attention to the need for help.

Because I had a stick it made it a visible disability, so she automatically helped. (Participant 1, mainly non-visibly disabled)

You know to use these aids they define you as a person to others, in that way you know always that he's got a white cane. He is blind, you know, and it's a big mental barrier but it also helps others understand your needs. (Participant 5, visibly disabled)

This aligns with evidence from previous research (Branham and Kane 2015; Hogan 2012) that the use of aids increases the stigma and the stereotype of dependence and vulnerability whereby assumptions may be made about the need for help. The public should not assume the need of help based on disability indicators, asking and respecting the response is the preferred strategy.

Non-visibly disabled participants had their eligibility to use public adjustments such as disabled bus seats questioned, whereas these were never questioned for the visibly disabled.

I often get on buses, and I sit in the front on the disabled seat, and I often get a look from older people like why are you sat there. But then I think I've just as much right to sit here as you do. (Participant 1, mainly non-visibly disabled)

This "policing" is widely noted (e.g. Dorfman 2019, 1051; Kattari, Olzman, and Hanna 2018, 481), because the non-visibly disabled defy what non-disabled people think disabled people should look like (Disability Unit 2020) which provokes less empathy (Cuff et al. 2016) and makes it difficult for disabled people to access the help and adjustments they need.

Relying on family

[Family] so it's a small network, isn't it? Yeah, we can help each other in different ways...we've all got different needs. (Participant 3, visibly disabled)

Family support and interdependence on families was widely noted among participants in managing independence and reducing the help needed in public spaces.

I don't often request help from strangers as I don't go out alone often. (Participant 6, non-visibly disabled)

Family support ranged from concern to helping with everyday tasks such as shopping, social companions, sighted guiders, drivers, and emotional support.

I am lucky I have a good wife, that drives me around, guides me and puts up with my down times, and puts up with my hoovering when I miss bits!! (Laughter). (Participant 5, visibly disabled)

Mingus (2011) referred to this as families providing ‘access intimacy’, relying on those who the disabled person feels safe with because they understand their needs and experiences of ableist societal barriers. The support of family is also evidenced by The *Family Resource Survey* (DWP (Department for Work and Pensions) 2023) which states that some 7% of the UK population (4.9 million people) provide informal care, and the NHS (National Health Service) (2015) acknowledge “carers make a critical and underappreciated contribution not only to loved ones, but to the very sustainability of the NHS in England”. Although the Government have implemented the *National Carers Strategy* (DHSC (Department of Health and Social Care) 2008) in recognition of their work, their reliance on them is increasing and budgets decreasing (House of Commons 2018). However, not all families are supportive, and the needs of those without such informal support is poorly recognised in policy and practice. As the provision of state means tested care undervalues the necessity of social support (Disability Unit 2021), which leaves disabled people in need of help from strangers in public spaces and may result in unmet needs and in some circumstances isolation (Barnes and Mercer 2010). This is particularly problematic for non-visibly disabled people, or those visibly disabled, but are not recognised as such, who may struggle to get their need for help recognised.

Not going

I won't go in because I know that it's unlikely I'm going to be offered help, and I know I'm not going to be able to carry it...It's almost like you have to explain yourself for help, and I can't. I know I can't... It's just not possible even like 2 handed. I wouldn't feel comfortable. It's just not an enjoyable experience. I wouldn't do it. (Participant 1, mainly non-visibly disabled)

One coping strategy in managing help mentioned by Participant 1 was the avoidance of situations where they would need to explain their non-visible disabilities to get the help needed. Braithwaite and Eckstein (2003), Pritchard (2021) also noted this strategy in controlling the need and costs of asking for help. This strategy stood out as potentially harmful as disabled people may miss out on participating in desired domains of activity, businesses miss out on engagement with a diversity of customers. It diminishes the understanding and awareness of strangers and public sector workers of the need of the non-visibly disabled for help, which may create a cycle of reduced understanding and avoidance for other disabled people. This coping strategy of avoidance may function as a guard against uncomfortableness around disability and discrimination (Temple, Kelaher, and Williams 2018), and may be provoked by stereotype threat, which threatens self-integrity, and prompts avoidance of situations that may include disclosure, judgement, or humiliation, which can undermine disabled people's wellbeing and life outcomes

(Silverman and Cohen 2014). It also highlights how the arbitrary notion of 'independence' emphasised by neoliberal ideology and the disability rights movement (Mladenov 2015), creates tensions of living in a society that strives for individual excellence. Although this notion of 'independence' can be empowering it can also undermine self-confidence, diminish self-esteem and provoke a sense of shame if help is needed, when in fact we are all interdependent on others. It needs to be acknowledged so that dependence can disassociate from moral failure, and social ideals positively change (Wendell 1996).

The public's behaviour in helping

Being offered help

It's so refreshing when that happens that doesn't happen very often, to be fair, but there are some nice people out there. (Participant 5, visibly disabled)

Offers of help from strangers restored faith in human kindness and humanity and made things quicker, easier and less obvious to others they were struggling. Offers were generally preferred to requesting help, were usually needed and accepted, and were beneficial for getting needs met. This contradicts findings suggesting that disabled people prefer to initiate help or accept offered help when it is clearly needed (Braithwaite and Eckstein 2003). However, these preferences may be biased due to a small sample and the fact that four out of six participants rarely received offers of help, which means they were more likely to welcome offers. It is plausible that disabled people who receive constant offers of help that lay within their capabilities (and therefore may be considered patronising), may have a different opinion.

Generally, this help is needed, or at the very least would make things quicker and less obvious that I am struggling. Whilst I'd like to do these things myself and often do, the help is wanted I would say around 70% of the time.... I would quite like more people to approach me and ask if I need help rather than me asking as if you do it often enough (daily as I do) you can feel like you are inconveniencing people from time to time. (Participant 4, visibly disabled)

This is in line with evidence that visibly physically disabled people often get more assistance from strangers than they want or need (Braithwaite and Eckstein 2003; Olkin et al. 2019). Although Participant 4 highlighted the positive aspect of being offered help, the notion of 'inconveniencing' others indicated their awareness of social exchange and the emotional costs, which may have practical consequences such as avoidance or isolation (Pulrang 2019). However, Participant 5, severely sight-impaired, rarely received offers of help, which is contradictory. It may be that helping experiences are different for

different disability groups as some disabilities may be easier to understand, have more public awareness campaigns, while others are more stigmatised or misunderstood, such as blindness which may still be one of the most feared of all disabilities (Rusu Mocănașu 2019).

Participants declined help, when there was not a need and managed these situations with a conscious effort not to put people off from offering in future (Nairo-Redmond, Kemerling and Silverman 2019), therefore interactions did not become hostile.

You do it in such a way that you think well I am not going to jar these people off, and next time a VI person needs some help they are still going to ask. (Participant 5, visibly disabled)

Being rejected or receiving 'unhelpful help'

I think they feel as embarrassed to help us, as we feel about asking other people. (Participant 5, visibly disabled)

I think some people are scared that they will offend you or that if something goes wrong, that you will blame them. (Participant 4, visibly disabled)

The lack of confidence, apprehension, caution, or embarrassment about helping mentioned by participants may connect with the societal fear of difference (Nairo-Redmond 2019). Although awareness raising around disability could dispel such uncertainties the traditional approaches to public education tend to focus on more common forms of disability and use a difficulties-based approach, rather than strengths and resilience (Reeves et al. 2022). A move towards a bio-psycho-social rather than medical model perspective may lead to improved intergroup relations to not only understand the need for help, but also the need for independence and autonomy.

Strangers also refused to help, being too busy, in a rush and some participants felt ignored. Asking required persistence until they got the help they required. Participant 2 demonstrated this confidence and perseverance:

Sometimes you talk to people and they kind of ignore you, for example, you try twice you say excuse me the first time, no response. Excuse me the second time, no response. So, I'll move on to the next person. As long as you get the information you need nothing else matters, the important thing is that you get the information you require. (Participant 2, non-visibly disabled)

as does Participant 5 in educating the public on their access rights,

I will say I think you will find I can, again it's about me as a person to have the confidence to say I can do it and I can spout the law at them. (Participant 5, visibly disabled)

whereas Participant 1 notes avoidance of situations needing help

If a coffee shop is busy and I can't see a table free near the counter, I won't go in because I know that it's unlikely, I'm going to be offered help. (Participant 1, mainly non-visibly disabled)

and Participant 4, humiliation and embarrassment when help is not forthcoming.

I can feel like 'I'm asking a lot of people to assist me with some very simple things and that can be quite humiliating and embarrassing because you lose feelings of motivation. (Participant 4, visibly disabled)

Negative social reactions of others may lead to internalised oppression and negative self-image. According to Foucault's analysis of biopower, disabled people may gradually succumb to subtle regulations and expectations of the social order (Policante 2010) which may reinforce what Foucault (1977, 1980) termed "regimes of truth" about disabled bodies, which affect their governance and control (Reeve 2002, 495–496), for example, if disabled people's access needs are not considered, if help is denied, or patronising or assumptive help received. This is important because the internalisation of societal ableism, stereotypes and prejudices held by the non-disabled majority, is perpetuated by systems of power that create and maintain it (Lorenzini 2016). Therefore, lower social positioning of disabled people is seen as 'truth', a powerful force influenced by culture, history and politics that reinforce that position.

These threats to self may be countered by individual strategies such as disassociation from disability and avoidance reinforced by the emphasis on cure stemming from the medical model, which creates social pressure to cope individually. Alternately, the collectivist strategies used by some participants such as persisting, educating and advocating derive from the social model that encourages disabled people to claim disability as a positive minority group membership (Nario-Redmond, Noel, and Fern 2013) and promote social justice (Branscombe et al. 2012). These differing mindsets may also relate to the diversity of disability and different degrees of disablement, individual personality characteristics, the individual's perceived place in societal structures, as well as the many intersecting identities alongside disability such as race and gender which influence how people respond to challenges in life (Brown and Moloney 2019).

Instances of assumptive and unconsented help happened to a severely sight-impaired acquaintance of Participant 5, when they were grabbed and taken across roads they did not want to cross, which was dangerous, disorientating, and an unacceptable act of violence nearing an assault.

I am sure the person doing the grabbing does it with the best intentions, but it really is excuse me, do you need help, how can I help you, simple. (Participant 5, physically disabled).

Such interactions and attitudes may have psychological and emotional impacts. Reeve (2002) refers to this as the psycho-emotional dimensions of disability, which may lead to internalised oppression, negative self-image, and low expectations (Mason 1992). Pritchard (2021) further notes that resistance to inaccessible spaces such as dependence or overcoming barriers are impacted by social attitudes to doing things differently and greatly impacts wellbeing. Assumptive help can also lead to further issues and need for help, Participant 1 had her bags assumptively put up high on a train.

I had men actually physically trying to take it off me while they're saying it, you know, like ohh, I'll help you with that and then they put it up somewhere high. And I'm thinking, yeah, but I don't know, you might be getting off before I do. And then it's all the way up there. So how am I going to get it back down again? (Participant 1, mainly non-visibly disabled)

Assumptive help prompted annoyance with the assumptions of the helper that the disabled person was unable to manage everyday tasks independently (Moss and Frounks 2022) and such actions are seen as unproblematic by non-disabled people (Dixon, Smith, and Touchet 2018), who are unaware of the reality of disabled people's experiences. The research results support Nadler's (2020) findings which suggest the use of negotiated help, which shows respect for independence, and involves the receiver of help as an equal and active participant in the situation. Therefore, asking and communicating a contract that leads into an agreed situation of help is recommended.

In addition to being denied help when requested and being a victim to unconsented acts of 'help', participants experienced barriers in executing their rights where aids had been provided. Participant 5 was refused entry to services with their guide dog, when in fact the guide dog was their agreed help, a mobility aid, making such acts illegal.

Although public sector services have a duty under the *Equality Act* (2010, 15) to allow guide dog owners access, Guide Dogs (2022) report that 81% of guide dog owners had been refused entry to public places in the past 12 months which has a negative impact on their daily lives, makes them feel "discriminated against", "unsafe" and "rejected".

The process of helping involved several layers of negotiations and interactions that shaped the encounter. These involved the expression of demand – the disabled person asked for help (or did not ask for help for various reasons) and negotiations of whom to ask and how. Subsequent, parallel or antecedent to the expression of demand was the offer of help (or the lack of it) from the side of the member of public. This was followed by the execution of the act of helping, either unconsented – the stranger provided support they felt was appropriate but without an agreed contract of the transaction with the disabled individual, or the disabled person was given a chance to reject or accept

the help and a contracted act of helping took place, which was the ideal, desired scenario. If the disabled person experienced barriers in the negotiations and decided not to express their demand for help, or there was no offer from the stranger, the disabled person was left without being helped. Such situations result in disabled people not participating in specific domains of activity which could negatively impact their wellbeing and life satisfaction.

The aim of the act of helping should facilitate increased participation and improve the quality of life of disabled people. However, the interactions between the helpers and the ones in demand of help are influenced by factors related to both parties. In addition, the situational contexts of barriers and facilitators in the physical and social environment play a crucial role in shaping the interactions, leading to nuanced negotiations of these interactions between the actors in the exchange – between expression of demand and offer (or their lack of) and subsequent acceptance or rejection in the execution of the help or helping.

Participants noted that during the COVID-19 pandemic they were less likely to receive help in public spaces due to their own, and strangers' caution and social distancing requirements. Public spaces had also become less accessible, with many struggling to navigate newly hostile and inaccessible public spaces.

I found it too stressful when the queuing was outside, traffic light systems, lines on the floor that I couldn't see, people getting angry, saying get back. (Participant 5, visibly disabled)

The initial policy protections were based on medical vulnerability (medical model) which left those not medically extremely vulnerable struggling to access food and services (Eskytė et al. 2020). Although this appeared logical on the surface it was an 'inappropriate proxy for the need for support in accessing food' (House of Commons 2020, HC1050). The social model was not implemented until later when thousands more disabled people were classified as needing extra support, offered by way of NHS volunteer responders, self-referrals for priority access to food delivery slots and dedicated shopping times for the non-shielding vulnerable (Parliament UK 2021). If an interaction model such as the bio-psychosocial model (Mitra and Shakespeare 2019) had been applied from the beginning, taking a staged approach to the support offered by looking at individuals level of functioning, the accessibility of new environments and ability to distance, and personal factors, such as family support and wellbeing, less disabled people would have felt abandoned without help.

Strengths and limitations

This qualitative study has provided an insight into the complex helping experiences of disabled people. Participants provided a trustworthy account of

their experiences which has raised important questions that can act as a platform for more representative future research and generalisable studies. The sample was small, and not representative of the diversity of disability and other intersecting identities such as ethnicity that may impact on helping experiences (Queirós, Faria, and Almeida 2017). The recruitment from disability groups, although provided access to hard-to-reach populations, may have influenced results, in that such collectives can be linked to higher disability activism and future methods may need to be carefully considered to incorporate individual and collectivist perspectives.

The experiences gathered were based on retrospective memories, and future studies may benefit from the use of diary methods, that have many accessible options of recording snapshots of experiences in context, that paint a holistic picture of everyday experiences over time, that individuals may dismiss as trivial, but may reveal the sociopsychological gravity of everyday prejudice (Hyers 2018), rather than a general idea of experiences.

Although accessibility of participant information and consent was planned for, further barriers to participation were discovered in the process. Some participants experienced difficulties completing the online form, or screen readers did not recognise the tick boxes. The assumptions that accessible software would overcome such barriers, or participants would request adjustments is not enough. The lessons about inclusivity and people's preferences to be offered help, rather than to request it learned in this research transfer to research methodology and recruitment of participants as well. Participant involvement in future research design would promote participant accessibility and input.

Conclusion

This study highlighted the interactionist nature of encounters of help. It aims to shift thinking from perceiving disabled people as lacking competence, while acknowledging that there are situations where disabled people depend on help provided by others. Therefore, discussing encounters of help takes into consideration the interactions between the strategies of disabled persons in negotiating specific situations of help in response to the public's behaviour and the context of the situation, its physical barriers or potential facilitators such as technology and other aids. Thus, explaining encounters of help from a bio-psycho-social perspective as an interaction between the individual and the environment can guide the understanding of how compounded they are. Their complexity is evident for example in the use of technologies and disability aids. Disabled people may deliberately use them as a communication tool to signify a need without having to ask for it, or they may avoid using aids in order to present as less vulnerable. While aids may serve as a practical tool to provide solutions, they may also lead to

perpetuating misconceptions about disabled people's needs, keeping them hidden or exaggerated. Public's behaviour, attitudes and responses shape disabled people's strategies in immediate and future encounters of help. Therefore, the focus needs to be on raising awareness of humanity which is central in encounters of help and shapes how specific disability aids and adjustments are used in particular contexts and situations.

Analysing encounters of help through the bio-psycho-social lens provided opportunities to deepen understanding and acknowledge the interactions between the needs of the disabled person and their environments. These interactions between the individual and the environment are contextualised through specific activities of meaningful participation where they take place and create a full picture of the encounter of help. Allowing opportunities for individually meaningful participation is key in truly following the rights of disabled and all individuals. Therefore, accessibility and offers of help need to be considered not only for basic needs, but in relation to a full range of activities that the individual chooses to participate in.

Several important insights were revealed in the study. Firstly, visibly disabled people were not always offered help despite the use of signifiers that bring attention to disability, whilst this may be an indication that stereotypes of disability are changing, sometimes help was needed. Secondly, differences in the frequency of offers were also apparent between visibly disabled groups, which suggests that further investigation is required. Thirdly, those non-visibly disabled were rarely offered help unless it was obvious that they were struggling, and therefore needed to request help, explain and justify their need for help. Their rights to use public adjustments were also questioned which created a barrier to their participation. Such intrusion into their personal realm and negative attitudes may lead some to avoid situations where they would need to ask for help, or use adjustments designed to help them. It highlights how the notion of 'independence' diminishes self-esteem and provokes a sense of shame in needing help. Dependence needs to de-establish from moral failure as we are all interdependent (Wendell 1996). Individual strategies such as avoidance are reinforced by the medical model's emphasis on cure, which creates social pressure to cope individually and implies the acceptance of stigma, reduces wellbeing, and does not combat social inequality. Alternately, a collective approach derived from the social model encourages disabled people to claim disability as a positive minority group membership (Nario-Redmond, Noel, and Fern 2013) and promote social justice (Branscombe et al. 2012), which was evident when some participants triumphed in persisting, educating others and asserted their rights to access. The interactionist perspective of the bio-psycho-social model acknowledges both.

Offers of help from the public restored faith in human kindness and made things quicker, easier, and discrete, yet assumptive and unconsented help was not acceptable in place of offers, as it was felt as dangerous,

disorientating and patronising by disabled people. Requests were sometimes ignored or refused by the public and required confidence and persistence until participants received the help needed. Not everyone is equipped with these characteristics, which may be due to the psycho-emotional dimensions of disability (Reeve 2002) and may lead to internalised oppression, negative self-image, and low expectations (Mason 1992).

Finally, all participants noted that the COVID-19 pandemic had impacted on their encounters of help as they and strangers were more cautious and anxious about the physical contact restrictions. More help was needed for many due to the initial blanket medical vulnerability approach taken and increasingly inaccessible public spaces, designed to meet the needs of the masses, however, it was rarely given due to hostile and individualist attitudes of some strangers. Policy assumptions of family support were made, which led those without, to fend for themselves in new stressful circumstances.

Policy implications

The social inclusion of disabled people is central to the UNCRPD (UN DESA 2006) as vital to the achievement of rights, as well as the Sustainable Development Goal (SDG 10.2) to empower and promote social, economic and political inclusion. Barriers to inclusion relate to legislation and institutional policy, physical, information and attitudinal barriers, where it is clear effective interventions are necessary to promote participation and empower disabled people in public spaces to achieve these goals (White et al. 2018).

The research findings generate some important policy implications. Firstly, they highlight the need for the promotion of public awareness, training, and education, based on the strengths and resiliencies of visibly and non-visibly disabled people which is vital to their wellbeing. Such awareness raising should promote not only the need for help, but also the need for autonomy, following the interactionist bio-psychosocial model. National media campaigns may also provide a useful tool in enabling honest conversations about implicit bias and ableism akin to #JustAskDontGrab. Engaging a wider non-disabled audience could shift attitudes and enhance awareness of implicit biases. The low-level everyday seemingly benevolent or neglectful acts can interfere with disabled people's feelings of belonging and inclusion. Therefore, aspiring towards seeing these unconscious actions could tackle direct discrimination towards disabled people.

A strong message needs circulating in promoting such awareness and education, that assumptive or unconsented help is not acceptable. Always ask a person what they want to happen, do you need help? how can I help? The public sector also needs to be aware that in times of cutbacks, not everyone has informal or paid support or wants it and that making a disabled person feel welcome and accommodated can make a real difference in

their lives. Another opportunity to promote public awareness and positive contact between groups is by encouraging public sector services to sign up to the Disability Confident Employer Scheme (DWP 2019). This will not only provide valuable employment to disabled jobseekers but also promote greater understanding of disability amongst employees and customers. It will positively impact their confidence and understanding of disabled peoples' needs and reduce the stigma and stereotypes of disability.

The findings highlight the importance of public services in advertising adjustments which can reduce anxiety about asking for them particularly for those non-visibly disabled. One such incentive may be through extending public sector endorsement of the use of the hidden disabilities sunflower lanyard (Hidden Disabilities 2023). Public education should seek to reduce the questioning of non-visibly disabled people in their use of public adjustments such as disabled parking spaces. The research highlighted that negative societal attitude can lead to avoidance of needed adjustments and potential isolation of disabled people. The provision of adjustments should be increased in line with the population statistics that around 17.8% of the population is disabled (ONS 2023) so there is less competition for them. The progression of the development of the provision of accessible technology and mobile applications should also be encouraged within public sector services, as they may provide greater confidence and independence, or a discreet way of asking for help, however, this is not a solution suitable for all and does not eradicate the need for human help.

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